

Health Literacy: Cancer Prevention Strategies for Early Adults



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Health literacy, the degree to which individuals have the capacity to obtain, process, and understand health information and services needed to make health decisions, is an essential element for early adults (aged 18–44 years) to make informed decisions about cancer. Low health literacy is one of the social determinants of health associated with cancer-related disparities. Over the past several years, a nonprofit organization, a university, and a cancer center in a major urban environment have developed and implemented health literacy programs within healthcare systems and in the community. Health system personnel received extensive health literacy training to reduce medical jargon and improve their patient education using plain language easy-to-understand written materials and teach-back, and also designed plain language written materials including visuals to provide more culturally and linguistically appropriate health education and enhance web-based information. Several sustainable health system policy changes occurred over time. At the community level, organizational assessments and peer leader training on health literacy have occurred to reduce communication barriers between consumers and providers. Some of these programs have been cancer specific, including consumer education in such areas as cervical cancer, skin cancer, and breast cancer that are targeted to early adults across the cancer spectrum from prevention to treatment to survivorship. An example of consumer-driven health education that was tested for health literacy using a comic book–style photonovel on breast cancer with an intergenerational family approach for Chinese Americans is provided. Key lessons learned from the health literacy initiatives and overall conclusions of the health literacy initiatives are also summarized.

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INTRODUCTION

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.¹ Numerous studies have demonstrated that low health literacy is a contributing factor to poor health status and outcomes, higher premature mortality rates, lack of adherence to medical recommendations, and higher direct and indirect health costs.^{2,3} The importance of health literacy is highlighted in a number of national plans and guidelines, *Healthy People 2020*,⁴ the National Academy of Medicine's Ten Attributes of a Health Literate Health Care Organization,⁵ The Guide to Community Preventive Services,⁶ recommendations from the U.S. Preventive

Services Task Force,⁷ and the National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care (CLAS Standards).⁸ These

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guidelines, informed by the peer-reviewed literature, describe multiple interventions focused on improving consumer understanding to inform decision making about prevention, early screening, and treatment to improve health outcomes and quality of life, and to reduce costs across chronic diseases and different types of cancer.^{2,3,9–14} This article, focusing on early adults (aged 18–44 years), addresses how evidence-based health literacy practices can improve patient education and system changes, and how community organizations can play a vital role in educating consumers about cancer prevention and engagement with healthcare providers.¹⁵

Recent studies have investigated the association of health literacy with cancer-related attitudes, knowledge, and behaviors to educate and increase patient trust, self-efficacy, and engagement in decision making.^{2,10–12} Systematic review of the literature on health literacy in early adults with and without chronic illnesses confirms the association of lower health literacy with poorer health behaviors and adverse health outcomes, and highlights their use of technology and the Internet as primary information sources.

HEALTH LITERACY APPROACHES TO CANCER PREVENTION

Findings from many studies confirm that low health literacy is one of the social determinants of health associated with cancer-related disparities, and that expanding partnerships with community-based organizations and consumers addresses unmet needs associated with cancer disparities.^{3,11–13} In Southeastern Pennsylvania, several health systems joined in efforts to improve health literacy for all patients. Nine hospitals participate in the Southeastern Pennsylvania Regional Enhancements Addressing Disconnects (SEPA-READS), a regional collaborative developed in 2010 and coordinated by two Philadelphia-based organizations, the Health Care Improvement Foundation and Thomas Jefferson University and Hospitals. Also, the National Cancer Institute–designated Fox Chase Cancer Center (FCCC) initiative has addressed health literacy across the cancer continuum, providing cancer education training and materials for healthcare providers and consumers throughout the region.

The multifaceted SEPA-READS initiative incorporates various program components and strategies based on best practices in the fields of education, health care, and public health. Education and peer learning are key drivers meeting SEPA-READS' objectives: (1) to enhance the capacity of healthcare systems and health professionals to address health literacy needs; and (2) to improve the ability of consumers and patients to communicate with providers and staff to increase capacity to effectively act on health information. Training for healthcare professionals employs a “train the

trainer” approach, to support internal staff education and sustained organizational change. Originally intended to benefit older adults with cardiovascular disease, the health literacy efforts of SEPA-READS are now applied to all ages of adult patients and consumers.¹⁶

CREATING A CULTURE OF HEALTH LITERACY

Health literacy interventions have the potential to be easily adapted in other contexts or to a targeted audience. FCCC, located in Philadelphia, integrates organizational, community, and research strategies to address health literacy across the cancer spectrum from prevention, treatment, and survivorship.

At the organizational level, health and patient educators spearheaded an initiative to build awareness about health literacy. Activities included an organizational assessment, identifying and training health literacy “champions” throughout the organization, and a standing committee to review patient education resources and materials. A health literacy guide on informed consent and technical resources was developed for the broader community.^{17,18} Easy-to-read educational materials were developed on a broad range of cancer topics, as FCCC developed and tested plain language text messages to address no-show rates on the mobile mammography unit and a text messaging intervention for low-income pregnant women smokers. Educational materials were developed at a sixth-grade reading level.¹⁹ Outcomes included a health literacy champion core facility to facilitate plain language clinical trial information, health literacy review of patient-related information, and assist researchers to develop innovative behavioral interventions for those with limited literacy (e.g., text messaging). Standard operating procedures for health literacy review and guidelines were instituted in public and research communications.

Specific practices taught as part of the SEPA-READS curriculum and incorporated in FCCC's health literacy programs include using plain language, confirming understanding through teach-back, and creating easily understood written and web-based materials. Implementing these practices are steps toward addressing communication barriers and promoting the prevention, screening, and treatment of cancer.

STRATEGIES TO ADDRESS CANCER COMMUNICATION

Early adults need access to information about cancer prevention and care that is easy to understand and linguistically appropriate. Screening for many cancers, including skin, cervical, and breast cancers, is critical for

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